

## Northside Meeting Notes - December 2014

### Business & Announcements

**Nancy B** led the holiday party meeting and approximately 28 people attended. There were no new members at the meeting. Thanks to all who brought a potluck dish and a toy to donate to Children's Healthcare of Atlanta. Over 30 toys were presented to CHOA and they were very much appreciated. The delicious food was enjoyed by all.

**Please Note:** The **January meeting** will be held on the second Saturday of the month, **January 10<sup>th</sup>, at Emory**, rather than on the regular date and location. At this meeting, Emory doctors will report on highlights obtained from attending the American Society of Hematology (ASH) conference that was held in December, where approximately 850 abstracts containing research results pertaining to multiple myeloma were presented. Over 30,000 hematologists attended the conference and there was standing room only in the myeloma conference rooms. Dr. Durie from the IMF is specifically looking at combinations of drugs and new options for relapsed myeloma. Research shows very promising results, so remember to stay positive! You are encouraged to bring any questions to the January meeting. At the **February meeting** a nurse educator from Millennium, who specializes in training non-myeloma healthcare personnel who treat myeloma patients, will join the group to educate and answer questions. You are encouraged to bring blood test results and ask questions about anything that you don't understand. **March is Myeloma Awareness month!** Please find out if your community has a St. Patrick's parade. If so, you are encouraged to contact the organizers and request to participate in the parade by wearing a T-shirt and carrying a banner (both provided by the IMF) that display "March Against Myeloma". The IMF will support your participation. Contact Nancy Bruno for further details. Remember that raising awareness expedites raising funds to find a cure!

### Discussion & Member Updates

There was a short meeting after the party. **Sandy** had some updates on members who have not been at meetings recently. With sorrow the group learned of the passing of **Inge**. We learned that **Earnestine** is doing much better and has begun taking Revlimid, Dex, and sub-cutaneous Velcade. She is getting dialysis twice a week and hopes to be able to join a meeting again soon. **Milton** is beginning a Phase 2 clinical trial, in which **Carolyn** is also planning to participate, which consists of combination agents Pomalyst, Daratumumab, and Dex. These newer generation drugs are understood to be more effective with less toxicity and side effects. **Lizabeth** was recently diagnosed with leukemia. The group was reminded that secondary cancers can sometimes occur because of some of the myeloma treatments. For example, there are a known low percentage of secondary cancers associated with taking Revlimid. **Irving** mentioned that he was recently diagnosed with AML, a type of leukemia, after taking 10 mg. Revlimid daily for a year. **Madge** has begun taking Elotuzumab and is doing well and her counts have been reduced consistently. **Monique** is

beginning Velcade now, after recuperating from recent health issues unrelated to myeloma. **Jim** mentioned that he had taken Revlimid before a stem cell transplant and planned to continue after the stem cell transplant for maintenance purposes, however when he took Revlimid post-transplant he could no longer tolerate it because he developed a rash, which did not occur before the transplant.

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## Southside Meeting Notes, December, 2014

**Doris M.** opened the meeting by leading the group in a moment of silence. **Gail M.** led the group in relaxation / breathing exercises. There were 15 present.

**Next meeting:** Our next meeting will be January 24<sup>th</sup> and will feature Emory Social Workers, Alice and Hillary, who will answer questions about Social Services and Myeloma. In February, Kim Nickels from The Leukemia & Lymphoma Society (LLS) will be present. In March, Tammie Rabern from Millennium: The Takeda Oncology Company, will be our guest speaker. March is also MM awareness month.

**ASH Report from Gail M.: The American Society of Hematology (ASH) met December 3-8 2014, in San Francisco, CA.** **Gail M.** was one of 10 Support Group leaders selected and supported by the IMF to attend this important annual meeting. Dr. Durie, Co-founder and Executive Director of IMF identified sessions that might most interest MM representatives. It was a very rigorous schedule with meetings scheduled from 7:00 am to 9:00 pm on most days. They all used Social Media to communicate from the meetings through blogs and tweets. Gail reported that research in Myeloma is moving very quickly as there are new drugs, new ways to use old drugs, and individualized genetic considerations on which therapy to use – or personalized medicine. In one of her blogs Gail reported: *“Here are three things that impressed me during my time in San Francisco for the 56th American Society of Hematology (ASH) Annual Meeting: #1 – Several patients in our group have been asked to meet with pharma companies and share our patient experiences. These highly profitable companies want to hear from you. No matter whether it’s strictly a business decisions, compassion, or a combination – they need to know how the drugs are working with you. #2 – With each presentation on drug therapy, the overriding question is about toxicity. We all know drugs, by definition, are toxic – but how to minimize risk is of great concern. #3 – This may seem small, but it is not insignificant. At each presentation on clinical trials, the researcher first thanked participating patients and their families, then funders, then colleagues, etc. This was more acknowledgement and respect for the contribution patients make to the advancement of cancer research than I have ever witnessed.”* Also, Drug companies stated patient assistant programs were underutilized. **If patients are having difficulty paying for medications, we must contact the pharma companies** -- they each have patient drug assistant programs. *“Moving to the data presentations, the definitions of MM are being revised. Going from MGUS to smoldering to active MM are more well-defined with categories including high risk, intermediate risk, and*

*standard risk. It's a different disease among individuals in the MM population, and can change over time in an individual. There is something about the Gene Expression Profile (GEP) that is important, cytogenetics I think it is called. Then there is the "light chain" abnormality that we have more to learn about."* Of particular interest were the sessions where worldwide experts debated and discussed myeloma issues – e.g., **1. Should Therapy be initiated for high risk smoldering Myeloma? Yes/No?; 2. Should Minimal Residual Disease (MRD) be used to guide treatment decisions?; 3- Should continuous therapy be the standard treatment approach in myeloma?; and 4 – Is intensive salvage therapy the preferred approach in relapsed/refractory myeloma?** In a second blog, Gail says to look for next-generation drugs – *"...daratumumab seems promising – being researched as a single agent and in combination with other familiar drugs."* Atlanta Support Group member from Atlanta, who was a special guest at an IMF-sponsored event and being honored for his community service, reported complete remission from a single agent therapy after only 2 months – for the first time after an MM diagnosis in 2000 and two transplants where he was in remission for 4 years the first time and 3 ½ years the second time. *"Trials are underway now for daratumumab with Revlimid (lenalidomide) and dexamethasone. Another drug in clinical trials, ixazomib (MLN9708), can mean a more comfortable once per week therapy. SAR650984 is an anti-CD38 monoclonal antibody. Did your eyes just glaze over? Who names these drugs anyway – is there any logical rhyme or reason for the complexity in naming them? C'mon! With all the next-generation therapies, we can begin to look at MM as more of a chronic disease than an incurable blood cancer. Gail said, "finally, we are learning that targeted therapy is our future. Myeloma treatment will be individualized therapy – for each individual genetic abnormality. So far, everyone got the memo to thank the patients and families who contributed to their research. This is fantastic. I think the translational research – Bench to Bedside to Curbside – is so much more successful with a fully engaged patient/family team."*

For more details about the ASH 2014 go to [www.myeloma.org](http://www.myeloma.org) there is a 90 minute video with Dr. Durie summarizing information learned during the conference. Click on -- "In case you missed it, click here for the Best of ASH 2014 replay".

## **Discussions: Focus for 2015**

**Pharmaceutical companies to expand resources:** It was suggested that we reach out to other pharmaceutical companies for support and resources to help address the needs of MM patients. Other pharmaceutical companies like **Celgene** makers of REVLIMID® and POMALYST®/IMNOVID®, THALOMID®/Thalidomide and Anti-CD38 Antibody: MOR202 in phase one of clinical trials; **Novartis**, makers of Panobinostat and Zometa; and, **Onyx** makers of Kyprolis® (Carfilzomib). **Millennium** makers of Velcade® (Bortezomib) has been very responsive to patient needs as their representative attends support group meetings and provides a luncheon at least once each year. Note: Millennium name has officially changed to The TAKEDA Oncology Company. Gail will start to look at funding opportunities.

**March is MM month – Alma** volunteered to lead the group's efforts and develop a plan to acknowledge March as MM month. A committee composed of Portia S., Pat C., Vena, and Selina B. will develop a plan for March 28<sup>th</sup> and as Multiple Myeloma "Move" Day. Instead of collecting proclamations, we will focus on radio and print media attention to Multiple Myeloma via local

newspapers that include Atlanta Voice, South Fulton Neighbor, Forest Park, Fayetteville, Riverdale, Cascade Patch, and the Douglas County Centennial. In addition this year we will commemorate MM month by hosting a MM Physical Activity Day at Greenbriar Mall. We hope this event can be a first-time fundraiser for our Support Group.

## **Announcements**

**Pillow Talk** is a project of CancerCare. This project provides literature and activities to assist individuals with initiating conversations about cancer. Members can go to [www.cancercare.org/pillowtalk](http://www.cancercare.org/pillowtalk) to obtain a package. Each package will contain (1) a Comfort Pillow Activity which provides one customized pillow, stuffing, fabric makers and cardboard keepsake hearts, (2) a Comfort Booklet which gives detailed instructions about customizing and designing your pillow; and (3) a CancerCare Fact Sheet which provides you and your family with useful information and tips on how to talk about cancer. Contact them to get your package.

**On The Wall-Paid Market Research Project**—On the Wall is an independent research company looking for people who have Multiple Myeloma. Those who qualify may participate in a study that will help learn more about how you deal with daily life. Each person who completes the study will be paid \$150. They will be using different ways to capture your story such as in-person interviews or online discussion groups and your personal information will be completely protected. Call 1-866-319-5251 between 8am and 5pm. Complete a short online questionnaire at <http://onthewall.com/10usspt/>.

**New Members:** We had two new members. **Geraldine** was diagnosed in November, 2013 after noting several symptoms: shoulder pain so severe she could not pull herself up, had little range of motion in her arm, nor could she hold the steering wheel of her car. She was self-medicating on 800 mg of Ibuprofen and Vick's vapor rub. An X-ray and other tests revealed cracked ribs, a broken collarbone, and porous bones. She was told she had MM. Her Myeloma responded to chemotherapy, she has harvested cells in preparation for a stem cell transplant. Geraldine is a Kaiser Permanente patient who is being followed at Northside Hospital but is experiencing a number of personal challenges to having a SCT that might very well negatively impact her health outcome. The group agreed to help direct her to resources, including members that maybe helpful. **Larry** was retired three months -- then had a car accident that resulted in his diagnosis of MM. The October 26, 2013, accident led to a CT scan at Grady identifying several spots on his spine. Doctors at Grady referred him to his primary doctor; his primary referred him to an oncologist in Stockbridge. He was told by this doctor that Myeloma is not curable, but is treatable. He received second opinions from Northside and Emory ultimately receiving chemotherapy and a stem cell transplant on July 24, 2014 at Emory. He is in complete remission taking Gabapentin and Acyclovir, but no maintenance therapy. He is seeing Dr. Kaufman at Emory Winship quarterly. To close the meeting, **Harold** led the group in song.